NEBRASKA HIV CARE AND PREVENTION CONSORTIUM (NHCPC)

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HISTORY OF THE NHCPC

The Nebraska Health and Human Services (HHS) HIV Prevention Program initiated a comprehensive community based participatory planning process in February 1994. Although there was no formalized process prior to that time, the HIV Prevention Program sought input related to prevention planning from community based providers and consumers. The process began with a forum of approximately 50 individuals impacted by, providing service to, or acting as resources for HIV related issues. The forum resulted in the creation of six regional planning groups, corresponding geographically with the six state health planning regions, and one statewide planning body. The statewide planning body was composed of 26 members including: two representatives from each regional group (12); two from each of the 5 risk populations determined by the epidemiological profile (10); two members at large (2); and two co-chairs, a state (HHS) co-chair and a community co-chair (2).

All six regional planning groups held their initial meetings during June 1994, with members selected after an extensive recruitment effort. Members were selected through a confidential nomination process, based upon parity, inclusion, and representation, as well as consideration of professional expertise needed to accomplish goals for prevention and care. Regional planning group membership averaged 15-20 persons, with slightly larger membership in the two areas of the state with the majority of the population.

The first fourteen months of Nebraska's community planning process proved challenging to both community participants and Nebraska Health and Human Services staff. Four HHS staff members acted as liaisons to the six regional groups, with technical assistance from three regionally based community health nurses as needed.

In late 1995, lengthy discussion was held at the statewide planning group meeting to discuss the purpose of the statewide planning body and how the role of the statewide group differed from that of the regional groups. A part of the discussion involved an estimated cost-benefit analysis. The result of the meeting was to disband the statewide planning body and leave primary planning efforts at the regional level. All participants recognized the need for the statewide coordination and communication that resulted in the creation of a formal standing subcommittee composed of regional co-chairs, regional community health nurses, and the State Community Planning Coordinator. In January of 1996, the HHS HIV Program Administrator re-assigned job positions by program function, resulting in one staff being identified to coordinate the entire community planning process. These changes supported a consolidated, yet specialized, communication network statewide and provided for more frequent and timely exchanges between regions and the HHS HIV Prevention Program.

From 1996 through 1999, the six regional planning groups met on a regular basis, depending upon their structure and bylaws. The regional co-chairs met about six times per year as a group to coordinate their efforts. Technical assistance was provided by internal and external sources as needed. Nebraska is a large rural state with 400 plus miles between the east and west borders, so great effort was made to ensure that all co-chairs shared the burden of travel by rotating the meetings across the state.

The regional planning groups were highly committed to the principles of community planning and did their best to achieve and maintain parity, inclusion, and representation; participate in setting priority populations and interventions; facilitate needs assessment, etc. However, the level of expertise and time needed to reach the outcomes desired by HHS and CDC became increasingly difficult for the regional groups. The fluidity of the regional groups significantly slowed the process, even though the new ideas, opinions, and information were of great value. The regional groups were also having difficulty staying motivated about planning in a low incidence state and few providers had the capacity to actually implement the interventions that were recommended.

During this time, the Ryan White Title II Consortia groups were experiencing many of the same challenges as the regional groups. The two meetings were being held "back to back". During 1998, the Ryan White Title II Consortia and the Regional Planning groups formally merged at the community level. Even though there was not a push on the national level to begin merging CARE and Prevention initiatives, Nebraska felt the need to do so. At the HIV Community Planning Leadership Summit in 1998, discussion began to reevaluate the community planning process in Nebraska. That meeting was the springboard for the restructuring of the CARE Consortia and community planning groups for Nebraska, which occurred over the next two years. Detailed analysis of multiple plans for consolidation and structure occurred over this time before the final structure was selected. Approximately nine months of development and transition time occurred before the first meeting of the Nebraska HIV CARE and Prevention Consortium (NHCPC) was held in March 2000.

The first meeting of the Nebraska HIV CARE and Prevention Consortium (NHCPC), in March 2000, began with an orientation to the Nebraska Health and Human Services HIV Prevention Program. Orientation included staff introductions, an overview of program functions and organizational structure, the history of the community planning initiative and the Ryan White Title II program, and the work of the Consortium. During the meeting, the purpose for the creation of the NHCPC, the objectives for the NHCPC, review of draft bylaws, operational guidelines, committee structures, and administrative issues (such as expense reimbursement and meeting logistics) were discussed. Members were provided orientation manuals which included the CDC Community Planning Guidance, the Ryan White CARE Act, general background information, the 1999 Comprehensive Plan, the current Statewide Coordinated Statement of Need (SCSN), the current Epidemiological Profile, general information on Robert's Rules of Order, organizational charts, member rosters, and instructions for expense reimbursement.

To ensure continuity and accountability in the community planning process, members ratified Bylaws (Attachment #1) and Operational Guidelines (Attachment #2) for the NHCPC in March 2000. These documents are reviewed and updated as needed at any regular or special meeting of the NHCPC. Written notice of the proposed changes are distributed to each member at least ten calendar days prior to the date of the next regular or special meeting. Changes require a two-thirds majority vote of the NHCPC members present.

NHCPC MISSION AND PURPOSE

The overall mission of the Nebraska HIV CARE and Prevention Consortium is to develop a Comprehensive HIV Care and Prevention Plan for the State of Nebraska. The plan will identify specific strategies and interventions that are responsive to validated needs within defined target populations. This mission will be accomplished in collaboration with the Nebraska Health and Human Services, HIV Prevention and Ryan White Title II Programs, the National Centers for Disease Control and Prevention (CDC), and the Health Resources and Services Administration (HRSA).

The purpose of the NHCPC is to act in an advisory capacity to the Nebraska Health and Human Services, HIV Prevention and Ryan White Programs. Through this advisory relationship, the HIV Prevention and Ryan White Programs will respond to the care and prevention issues affecting those at risk for becoming HIV infected, as well as those who are currently living with HIV/AIDS. A Hepatitis Prevention Program was added in 2002. Integration of Hepatitis prevention education with HIV prevention has become an integral part of the overall program.

NEBRASKA DEMOGRAPHICS

The Nebraska HIV CARE and Prevention Consortium (NHCPC) has been structured to be mindful of parity, inclusion, and representation. Factors such as race/ethnicity, geographic areas, risk behaviors, professional expertise, and affected and infected populations are considered when structuring the organization (Attachment #3). Additionally, Nebraska is a large rural state with a growing minority population. According to the United States Census Bureau 2000 census, Nebraska's total population is 1,711,263. Of the total Nebraska population, 5.5% are Hispanic or Latino, 4% are Black or African American, 1.3% are Asian, 1% are American Indian and Alaska Native, and less than 1% are Native Hawaiian and Other Pacific Islander.

The large geographic area of Nebraska creates unique challenges for service providers. Successful public health initiatives in the areas of prevention and care/treatment issues require attention to service availability, gaps/barriers to services, and participation by those residing in the community. The social norms, values, and resources may vary according to each area of the state and its proximity to other communities. These issues support the need for geographically diverse representation in the planning process. Issues must be prioritized based on a number of factors including economic feasibility, programmatic effectiveness, community acceptance, existing capacity for implementation, and the like. These issues support the need for geographic representatives to ensure the process is inclusive of the needs of all affected Nebraskans.

THE CURRENT NHCPC

The NHCPC currently allows up to 38 positions. The members are classified as either "standing" positions or "elected" positions.

Standing positions are filled by persons required by federal funding and administrative recommendation to ensure specific expertise, which is critical to HIV prevention and care through public health forums. Persons identified to serve in these positions are appointed by the HIV Program Administrator upon recommendation by members or HIV Prevention Program staff. These positions comprise no more than 1/3 of the total membership.

The elected positions represent related functional areas, persons directly impacted by the epidemic, and geographic representatives. Persons identified to serve in these positions are determined by the Membership Committee of the NHCPC based on the current HIV epidemiological profile of the state and on the principles of parity, inclusion, and representation.

The Membership Committee assesses the need for specific classification positions for the NHCPC periodically and makes recommendations to the full membership to coincide with future elections. These members comprise the remaining 2/3 of the membership. Of that 2/3, six regional representatives are elected by their respective regional community planning group. The membership positions of the NHCPC (Attachment #4) are:

NOTE: Currently, there are three slots open and awaiting specific designation in 2004.

Regional Representatives (represent the six regions)

- Central Region
- Eastern Region
- Northern Region
- Southeast Region
- Southwest Region
- Western Region

Populations at Risk

(represent at-risk populations)

- Injecting Drug User
- MSM Rural (+ or -)
- *MSM Urban* (+ or -)
- MSM of Color
- Person Living with HIV or AIDS (2)
- Red Ribbon Community
 (HIV Positive persons advisory group)
- Woman at Risk Affected or Infected

<u>Community Stakeholders</u> (represent community organizations)

- City / County Health Department
- Counseling and Testing
- HIV Case Management
- Mental Health / Substance Abuse
- Minority Community Based Organization (CBO)
- Minority HIV Impacted
- Prevention Subgrantee

Standing Positions

(represent key functions for the process)

- Adolescent and School Health (NDOE)
- Ryan White AIDS Drug Assistance Program (ADAP)
- Behavioral Health (2)
- Direct Provision for STDs
- Epidemiologist
- Medicaid Issues
- State Community Co-Chair
- State Corrections
- State HIV Program Administrator (Ex-Officio)
- Ryan White State Title II Program Manager
- Ryan White Title III Coordinator (2)

Nominations for membership to the NHCPC are solicited through an open process and candidates are selected based on criteria established by the NHCPC and the HHS HIV Prevention Program. The nomination and selection of new NHCPC members by the Membership Committee occurs in a timely manner to avoid vacant positions or disruptions in planning. In addition, the recruitment process for membership in the HIV prevention community planning process is proactive to ensure that socio-economically marginalized groups and groups that are underserved by existing HIV prevention programs are represented.

The NHCPC actively recruits new members who represent a variety of perspectives of those affected by HIV and includes racial/ethnic, age, and geographic diversity of the state. Members represent the affected community in terms of race/ethnicity, gender/gender identity, sexual orientation, and geographic distribution.

A wide variety of areas of expertise are available to the NHCPC, both through its membership and HHS HIV Prevention Program staff involved in the planning process. Members are selected using the following criteria:

- ➤ The nominee reflects the characteristics of the current and projected epidemic (as documented by the epidemiologic profile) in terms of age, gender, race, ethnicity, and socio-economic status, geographic distribution (urban and rural residence), and risk for HIV infection.
- ➤ The nominee represents one or more of the following constituencies:
 - a. state and local health departments, including HIV prevention and STD treatment programs;
 - b. state and local education agencies;
 - c. epidemiology;
 - d. behavioral and social sciences;
 - e. program evaluation;
 - f. health planning;
 - q. consumer or public;
 - h. other relevant agencies (e.g. substance abuse, mental health, corrections).
- > The nominee is able to fulfill the commitments to the work of the NHCPC.
- ➤ The nominee is able to relay pertinent information between the NHCPC and his/her constituency in the community.

To assure needed input without the NHCPC becoming too large to function, the NHCPC seeks additional avenues for obtaining input on community HIV prevention needs/care and priorities such as conducting focus groups and key informant interviews.

The application process to fill an elected position on the NHCPC is administered and monitored by the Membership Committee, with assistance from the State Co-Chair. Applications for membership are available at each NHCPC meeting, from the Chair and State Liaison of the Membership Committee, State Co-Chair, and on the HHS HIV Prevention Program website at www.hhs.state.ne.us/dpc/HIV.htm (Attachment #5).

A cover letter is attached to applications outlining each vacancy or upcoming position availability, so applicants are aware if a position category is applicable to them. All completed applications are submitted to the State Co-Chair for duplication and filing purposes. The State Co-Chair submits copies of the applications to the State Liaison of the Membership Committee for review. The State Liaison coordinates with the Chair of the Membership Committee to conduct a conference call with all members of the committee to discuss applications and determine who will be placed on the ballot for elections. The State Liaison notifies the State Co-Chair of the final slate of nominees. The State Co-Chair constructs the ballots and elections are held at the next regular NHCPC meeting.

Members serve for a period of three years, except for standing members, whose service is indefinite until such time as they deem they can no longer serve. Members are elected at the last official NHCPC meeting of the calendar year and take office on January 1 of the following year. Terms expire on December 31. Members of the NHCPC may not serve more than two consecutive terms.

The NHCPC is directed by two co-chairs. The State Co-Chair is appointed by the HIV Program Administrator. The second, Community Co-Chair, is elected by the NHCPC membership at the third official meeting of the calendar year and takes office on January 1 of the following year. Terms expire on December 31. The Community Co-Chair serves for a period of two years. He/she shall not serve more than two consecutive terms. The Community Co-Chair must be a member of the NHCPC for six months prior to election.

Active participation from members on the NHCPC is critical for the work to be accomplished in a timely and efficient manner. The membership structure of the NHCPC is designed to bring new voices to the "table" on a rotating basis to allow for comprehensive involvement by the community. Because the number of meetings for the NHCPC and its standing committees will be limited, it is important that all members are prepared to fully participate at each meeting.

New members are provided an orientation session prior to their attendance at their first meeting. The Membership Committee, in collaboration with the NHCPC Co-Chairs, provides orientation sessions as needed for new members joining the group. A verbal orientation, along with an orientation guide (Attachment #6) and membership manual, is given to each new member.

Any individual member currently serving on the NHCPC may request update training or technical assistance if such training/assistance is felt to be needed to more fully participate or understand the community planning process. The Membership Committee, with the assistance of the NHCPC Co-Chairs, facilitates access to the requested training as appropriate and upon approval by the HHS HIV Prevention Program.

The Nebraska HIV CARE and Prevention Consortium (NHCPC) has met at least four times per year since its inception in March 2000. The work of the NHCPC is primarily accomplished in the committee meetings. Time is set aside during the NHCPC meeting for committees to meet. The agenda for the quarterly meetings is distributed at least 10 days prior to each meeting and public notices are distributed statewide and posted in accordance with Nebraska Open Meeting Laws.

In making recommendations to HHS, the NHCPC must operate in compliance with all applicable state and local conflict of interest laws. In order to safeguard NHCPC recommendations from potential conflict of interest, each member discloses any and all professional and/or personal affiliations with agencies that may pursue funding. An annual Disclosure of Conflict of Interest Statement (Attachment #7) is completed by each member and kept on file with the Community Planning Coordinator. On issues where a member's affiliate is the potential recipient of funds, that member may not vote on that issue or formally review that affiliate's request for funds or other supports.

The NHCPC has five standing committees. Each standing committee has a State Liaison appointed by the HIV Program Administrator. The role of the liaison is to facilitate the work of the committee and serve as a resource for materials, information, direction, and provide technical assistance as needed.

All members of the NHCPC are expected to serve on a committee during their term of membership. Supporting the NHCPC philosophy of broadening community involvement to ensure parity, inclusion, and representation in all aspects of the process, persons outside the NHCPC membership may be solicited to participate on committees and ad hoc groups or task forces. Each committee elects a chair, who must be a member for six months prior to election, to direct the activities of the committee. The committee chair must be a current member of the NHCPC and ensures the committee operates under the Bylaws and Operational Guidelines.

The NHCPC standing committees and purposes of each are as follows:

Assessment and Evaluation Committee

Review and identify strengths and weaknesses and provide recommendations regarding prevention and care evaluation and assessment processes and results.

Care Services Committee

- ➤ Review the continuum of services provided by the Ryan White Title II Program and provide feedback to the Ryan White Program regarding adequacy of services.
- Provide recommendations to the Title II Program regarding the addition/deletion of provided services.
- Research and provide information, as necessary, to identify additional services and assist in their procurement as necessary.
- Assist in the development of additional resources for service provision.

Interventions Committee

➤ Utilize statewide needs assessment information for the purpose of identifying, prioritizing, and recommending behavioral interventions for funding with HIV prevention funds. Effectiveness and support for these interventions should be based in behavioral change theory, be cost effective, and compatible with the norms, values, and relevance for the communities where they will be introduced.

Membership Committee

➤ Recruit elected members and orient all participants. The committee will solicit new members under the guiding principles of achieving parity, inclusion, and representation of the epidemic for the NHCPC. Personal knowledge and expertise will be sought for positions, which contribute critical information to the development of a comprehensive HIV care and prevention plan.

Public Information Committee

➤ To review proposed educational materials, to discuss media and education that is made available to communities, make recommendations for educational materials, and participate in the development of a public information plan.

The NHCPC Co-Chairs, to fulfill time-limited objectives, may, as needed, designate ad hoc groups. Chairpersons for ad hoc groups are appointed by the NHCPC Co-Chairs and report to the NHCPC Co-Chairs for the duration of the appointment. The Chairpersons for ad hoc groups must be members of the NHCPC.

Ad Hoc committees are appointed to meet special needs or complete special tasks as identified by Nebraska HIV CARE and Prevention Consortium members. In 2001, a Priority Populations Ad Hoc committee was formed and charged with the task of developing a more objective, systematic approach to defining priority populations. A second Ad Hoc committee was appointed to review the Bylaws and Operational Guidelines of NHCPC and recommend changes to the membership. Both committees were retired once their task was completed.